National Aboriginal Council on HIV/AIDS

First Progress Report
2001-2003

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2001-2003
(April 2004)

Developed by
the National Aboriginal Council on HIV/AIDS and Health Canada

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Health Canada Santé Canada

Dedication to Todd Armstrong

Todd Armstrong, a former member of the National Aboriginal Council on HIV/AIDS (NACHA), passed away on September 14, 2003. NACHA would like to dedicate this progress report to the memory of Todd, whose tireless efforts on behalf of NACHA, as well as the many other people he touched, will never be forgotten. Below is a copy of the letter NACHA sent to Todd's family after his passing.

November 3, 2003

Dear Audla, André and Todd's siblings,

Todd was a member of many committees and group within the Aboriginal AIDS movement. His contributions were significant and his dedication to the Inuit population unquestionable. One of these committees was the National Aboriginal Council on HIV/AIDS (NACHA), an advisory body to Health Canada regarding all policy related to Aboriginal HIV/AIDS initiatives under the Canadian Strategy on HIV/AIDS.

Todd's role in NACHA began years before the Council itself was formed. He contributed to the development of the Council through long and often intense meetings with colleagues from across Canada, representative of the three Aboriginal Peoples. Todd's creativity and good humour helped to keep the process moving forward. When the Council was formed, Todd took on the role of Co-chair, helping to conduct the work of the Council between meetings and take a lead on behalf of his caucus colleagues to share information and decisions with the other 3 caucuses.

There are really no words to express our deep sympathy and shared sense of loss following Todd's passing. As a group we have drawn strength from the wisdom and guidance of the Elders who are a part of our Council. Todd's good energy, humour and tenacity have left their mark on NACHA in so many ways. Our work will carry on with determination to honour Todd's spirit and follow the good path he began to create with us.

Yours in the Spirit of Healing,

NACHA

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1.0 Introduction

The National Aboriginal Council on HIV/AIDS (NACHA) was formally established in May 2001 to provide advice to Health Canada on HIV/AIDS issues that affect all Aboriginal peoples in Canada and examine the impact of the disease on Aboriginal communities. The creation of this advisory body was the result of many years of consultation, collaboration and cooperation among the vast spectrum of stakeholders committed to and responsible for HIV/AIDS in their respective constituencies and populations.

NACHA represents four unique groups – First Nations, Inuit, Métis and the Community (made up of Aboriginal AIDS organizations/Aboriginal Peoples living with HIV/AIDS), and has room for 24 members. As of February, 2004, there were 19 members. The establishment of this Council provides Health Canada with the opportunity to seek their meaningful input into all its decisions which affect Aboriginal people under the Canadian Strategy on HIV/AIDS (CSHA). The governance structure of the Council has evolved over the past two years to designate the four elected caucus co-chairs to act on behalf of the Council in between Council meetings or when the Council as a whole cannot be consulted directly. Caucus co-chairs were elected at the face-to-face meeting following the Second Aboriginal Summit on HIV/AIDS in Calgary in 2001 (See Appendix 1.0).

Since its inception in May of 2001 NACHA has been in the process of defining itself and evolving, and that evolution is still taking place. This evolution has taken the form of the development of procedures and structures to ensure that the Council runs smoothly and the absorption of the standing committees within Health Canada to address Aboriginal issues.

Here**,** Aboriginal HIV/AIDS issues can be discussed and debated and recommendations made on how best to approach the epidemic within the specific populations represented at the table and in the Aboriginal community as a whole. The result has been an increased awareness of Aboriginal HIV/AIDS issues at government level, with consistent Aboriginal community input into Health Canada decisions that affect Aboriginal people under the CSHA, as well as the fostering of cross-cultural understanding between the various groups sitting on the Council.

NACHA provides expertise and advice on HIV/AIDS-related issues, from surveillance to community-based research to resource allocation, and acts as a “one-stop shop” when it comes to providing an Aboriginal perspective and advice both to Health Canada and other CSHA stakeholders. Because members of the Council are drawn from the Aboriginal community, NACHA acts as both a liaison back to that community and serves the function of an advisory, communication and coordination mechanism for the federal government, as well as being accountable to its communities. It also acts as a direct pipeline for issues from the Aboriginal community to be brought to Health Canada. And although the Council, in terms of its membership, role, and its structure**,** continues to evolve, it will continue to be a valuable resource for the federal government and the Aboriginal community alike in maintaining mutual communications and ensuring that Aboriginal HIV/AIDS issues are addressed by the Government of Canada in a timely fashion.

Over the years there have been many different Aboriginal committees struck to advise the government on HIV/AIDS issues among Canada's Aboriginal population. NACHA was created to centralize these efforts, and to minimize the duplication of work within isolated committees. Two examples of these former committees whose work has been absorbed into NACHA are the Medical Services Branch Focus Group and the Laboratory Centre for Disease Control Aboriginal Working Group.

One of the earliest advisory committees on Aboriginal HIV/AIDS issues was the Medical Services Branch (MSB) focus group, now called the First Nations and Inuit Health Branch, which was formed in 1991. This group helped to direct funding and efforts from the MSB to program initiatives on-reserve and in Inuit communities. Although defunct before the inception of NACHA, the MSB focus group accomplished much during their existence, including the creation of Guidelines for the Development of HIV/AIDS Programs and Services, and the development of criteria for eligibility for funding under the MSB HIV/AIDS funding program, which helped focus efforts in communities where they were needed.

For many years the Laboratory Centre for Disease Control Aboriginal Working Group on HIV/AIDS guided and advised the Laboratory Centre For Disease Control on issues that would effect HIV/AIDS surveillance, research and epidemiology efforts among Aboriginal people in Canada. These efforts would lay the ground work for the start of community-based HIV/AIDS research in the Aboriginal community in Canada, and make the findings of this statistical research and the language of epidemiology more accessible, and therefore more useful, to the Aboriginal HIV/AIDS community. *Understanding Epi: A Guide To HIV/AIDS Surveillance Among Canada's Aboriginal Community*, created in partnership with the Canadian Aboriginal AIDS Network, was a significant project by this committee to demystify the language and approach of researchers and epidemiologists to the Aboriginal community in Canada, and thereby improve the essential relationship between communities and those who monitor the spread of disease among Aboriginal populations in Canada.

2.0 National Aboriginal Council on HIV/AIDS

2.1 Background

The idea of having a National Aboriginal Council on HIV/AIDS which lends its expertise and advice to Health Canada has been around almost as long as the epidemic of HIV/AIDS among Aboriginal people was publically identified in the late 1980s. When this public recognition was first made, a small group of Aboriginal people were already working within their communities to stop the spread of the virus and address the health issues of their people. It was these small groups of activists who were first invited to sit on the various advisory groups within Health Canada that were starting to recognize and to deal with the epidemic in Aboriginal communities. The idea of amalgamating these groups into one large national committee was first raised on these individual committees. Participants on these various Aboriginal advisory committees realized that it was often the same people sitting on each and that the work was sometimes being duplicated. In July of 1997, various activists from the Aboriginal community met with Health Canada in Ottawa to discuss the creation of a single national committee. The seed was planted, and the idea of a national council would begin, over time, to grow.

After many years, much debate and discussion, the first National Aboriginal Council on HIV/AIDS was elected at the 2nd Aboriginal Summit on HIV/AIDS in Calgary in May 2001. (See Appendix 1).

2.2 Role of the Council

The role of NACHA lobbies in order to ensure that the HIV/AIDS related needs of all Aboriginal people are being met and acts as an efficient mechanism by providing advice to Health Canada and other stakeholders about the needs of all Aboriginal people in Canada. The role of the Council is to:

- increase collaboration between all Aboriginal peoples and all other Strategy stakeholders
- increase communication with Aboriginal communities and Aboriginal community members
- increase the cost effectiveness of Canadian Strategy on HIV/AIDS resources
- increase cross-cultural awareness and support in the work of NACHA between all Aboriginal peoples and all non-Aboriginal peoples.
- create one central committee to replace/absorb existing Aboriginal consultative committees of the CSHA

3.0 HIV/AIDS Among Aboriginal People of Canada

Over the past decade, the AIDS epidemic has risen steadily in the Aboriginal population in Canada. According to the latest "HIV and AIDS in Canada Surveillance Report to June 30, 2003," published in November 2003, of the 18,934 AIDS cases reported to the Centre for Infectious Disease Prevention and Control as of June 30, 2003, a total of 16,244 (85.8%) contained ethnic information, and of these, 509 were reported as Aboriginal persons (3.1%).

The proportion of reported AIDS cases among Aboriginal people increased from 1.5% before 1994 to 9.7% in 1999, followed by a drop to 5.5% in 2001 and a subsequent rise to 12.9% in 2002.[1]

Aboriginal people continue to be over-represented in the HIV epidemic in Canada. They represent 3.3% of the Canadian population[2], and yet an estimated 3,000 to 4,000 Aboriginal people were living with HIV in Canada in 2002, representing about 5% to 8% of all prevalent HIV infections. This is higher than the 1999 estimate of 2,500 to 3,000, or about 6% of the total. Aboriginal people accounted for approximately 250 to 450 of the new HIV infections in Canada in 2002, or 6% to 12% of the total, as compared with 9% in 1999. The composition of exposure category among Aboriginal people newly infected in 2002 was similar to that in 1999. The distribution in 2002 was 63% injection drug users (IDU), 18% heterosexual, 12% men who have sex with men (MSM), and 7% MSM-IDU. It is important to note that the proportion of newly infected Aboriginal Canadians who are IDU (63%) is much higher than among all Canadians (30%). This indicates the different characteristics of the HIV epidemic among Aboriginal people and underscores the complexity of Canada's HIV epidemic. [3]

There are important aspects to surveillance among Aboriginal communities to keep in mind:

- caution must be used when looking at proportions as they can change considerably with the addition of one case particularly when total numbers are small;
- a large number of Aboriginal people with HIV infection may not yet be diagnosed and therefore not captured in surveillance data;
- over 15% of reported AIDS cases and nearly 13% of positive HIV test reports were not identified as being of one specific Aboriginal community;
- ethnicity is not reported to the Centre for Infectious Disease Prevention and Control by all provinces and territories;
- ethnicity is not always known for new HIV/AIDS diagnoses.

Transmission of HIV is facilitated by high rates of sexually transmitted diseases, substance abuse, and other health and social issues. Unemployment, low incomes, receipt of social

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[1] *HIV and AIDS in Canada: Surveillance Report to June 30, 2003*, Health Canada

[2] Statistics Canada. *Aboriginal peoples of Canada: a demographic profile*. The Daily. Cat. no. 96F0030XIE2001007, January 2003.

[3] *Canada Communicable Disease Report.* 1 December, 2003 Volume 29, Number 23

assistance, lack of stable housing, low educational attainment, and mobility have been identified as risk factors in recent studies of Aboriginal people with HIV/AIDS. Other HIV/AIDS risk factors associated with socio-economic status include low rates of condom use, increased risk of sexual abuse or non-consensual sex, poor self esteem and inability to demand safe sexual practices or decline sex, increased alcohol and drug use which predisposes to high risk behaviours and over representation of Aboriginal people in settings where there is an increased risk of HIV contact, such as in prison and on the street.

The Aboriginal component of the CSHA is characterized by active participation of Aboriginal people and dedicated funding to this population in on-reserve, rural and urban locations. It is a broad strategic response involving the areas of prevention, community development, care, treatment and support, epidemiology and surveillance and improved coordination of HIV programming.

3.1 Critical Issues for the Four NACHA Caucuses

3.1.1 HIV/AIDS and Aboriginal Community-based AIDS Organizations and Aboriginal People Living with HIV/AIDS

Structural and jurisdictional factors in the provision of health services to Aboriginal communities result in issues which span HIV/AIDS prevention through the treatment/support continuum. Geography, isolation and small community size influence accessibility to services and comprehensiveness of services in communities. The jurisdictional split of certain health services between the federal government (First Nations on reserve and Inuit communities) and the provincial governments (non-reserve populations, including non-status, First Nations off-reserve and Métis) may cause gaps in services, poor continuity of care, difficulties in accessing services and funding restrictions to Aboriginal AIDS service organizations. Access to services can also be impeded by cultural differences in the types of health programs offered or the way they are delivered. Aboriginal people have advocated for the provision of health services by Aboriginal professionals, in the community if possible, using educational materials and processes which are sensitive to language and culture.

Traditional practices which have been reported as successful or beneficial include those founded on the Medicine Wheel and Healing Circle, and Aboriginal holistic approaches to healing. Communities themselves may present barriers to care through restrictive values which do not welcome Aboriginal people with HIV/AIDS into communities, or a lack of financial and human resource capacity to deal with HIV/AIDS.

Issues that have been raised in the past concerning the CSHA funding processes include a lack of capacity in Aboriginal communities to prepare successful project proposals, and concerns that existing processes are inequitable and not culturally sensitive. These issues are currently being addressed by advisory bodies and consultative processes of the funding programs, which have instituted changes such as peer review of proposals which rely on a majority Aboriginal committee, as well as including criteria which look at project relevance.

Aboriginal people desire a greater participation in decision making processes when relevant government policy is developed or other issues of importance to Aboriginal people are discussed by governments. A climate of partnerships has been fostered by the federal 'Gathering Strength' approach, and has resulted in Aboriginal participation in joint steering committees, working groups, advisory bodies and inter-jurisdictional collaborations. HIV/AIDS approaches and strategies require Aboriginal ownership and control for maximum effectiveness, aided by links to federal and provincial services, capacity building and community development, a holistic approach, and a focus on special groups such as youth, women and injection drug users.

3.1.2 HIV/AIDS and First Nations

Issues of jurisdiction, self-government, representation and land-claims are still being played out between First Nations communities and all levels of government across Canada. Issues of poverty, racism, and other forms of societal abuse both contribute to increasing rates of HIV among First Nations and compromise services to those living with the disease both on reserve and in urban areas. Although the past ten years have seen a number of First Nations-specific AIDS organizations develop in Canada, lack of funding and a poor grasp of the issues on the part of non-Aboriginal populations has meant that incidence of HIV infection continues to increase within First Nations populations.

Improved, secure funding to support First Nations -specific initiatives at the national, regional and community level is urgently needed to attempt to address the epidemic among First Nations. Programs which honour culture and truly reflect community life can help First Nations recognize the risk HIV. Funding must support community action which promotes ownership of HIV/AIDS prevention and education programs, and encourages the development of care**,** treatment and community support programs in First Nations communities on and off reserve.

Any initiative, program or service information intended for First Nations must be provided in a format which is accessible and linguistically appropriate to be effective. Financial constraints or population- based formulas that do not realistically address the actual costs of providing information or services in diverse urban, rural and isolated areas of Canada cannot justify a lesser commitment to the prevention of HIV/AIDS among First Nations or to the development of care, treatment and support services for First Nations living with HIV/AIDS.

While partnerships between Inuit, First Nations and Métis organizations can be of benefit, such partnerships cannot take the place of First Nations-specific projects and programs. Government and Aboriginal HIV/AIDS organizations must acknowledge, respect and honour the cultural differences between Canada's Aboriginal peoples, support First Nations-specific initiatives and recognize their limitations with respect to meeting the HIV/AIDS-related needs of First Nations.

3.1.3 HIV/AIDS and Inuit

The majority of the 45,000 Inuit live in the 53 remote communities of Arctic Canada. Both Ottawa and Montreal have substantial, organized Inuit communities. Most often, Inuit are statistically included within larger Aboriginal statistics, as Inuit-specific HIV/AIDS statistics are scarce.

Inuit-specific projects and programs have been implemented over the past several years but Inuit awareness of HIV/AIDS issues remains lower than other Aboriginal and non-Aboriginal populations. The lack of strong prevention activities has created a situation in which Inuit are at an ever increasing risk of becoming infected with HIV.

Improved, secure funding to support Inuit-specific initiatives at the national, regional and community level is urgently needed to attempt to prevent an epidemic among Inuit. Programs which honour culture and truly reflect community life can help Inuit recognize the risk HIV. Funding must support community action which promotes ownership of HIV/AIDS prevention and education programs, and encourages the development of care**,** treatment and community support programs in Inuit communities.

Any initiative, program or service information intended for Inuit must be provided in a format which is accessible and linguistically appropriate to be effective. Financial constraints or population- based formulas that do not realistically address the actual costs of providing information or services in the Arctic cannot justify a lesser commitment to the prevention of HIV/AIDS among Inuit or to the development of care, treatment and support services for Inuit living with HIV/AIDS.

While partnerships between Inuit, First Nations and Métis organizations can be of benefit, such partnerships cannot take the place of Inuit-specific projects and programs. Government and Aboriginal HIV/AIDS organizations must acknowledge, respect and honour the cultural differences between Canada's Aboriginal peoples, support Inuit-specific initiatives and recognize their limitations with respect to meeting the HIV/AIDS-related needs of Inuit. They must increase their understanding of Inuit culture and the needs of urban Inuit because urban Inuit are often served by urban Aboriginal AIDS organizations.

3.1.4 HIV/AIDS and Métis

One of the hardest things to do is to generalize about the Métis community because the Métis people are very diverse. It is estimated that there are approximately 300,000 Métis people throughout the Métis homeland, which spans from Ontario to British Columbia. Between dialects, urban, rural, small towns and provinces, it is impossible to find a “one size fits all” solution when it comes to the education of Métis people on HIV/AIDS.[4]

Métis culture and language differences make it difficult for non-Métis to provide safer sex education in a way that will be accepted and understood by Métis people. The high degree of movement of Métis people between inner cities and rural areas may bring the risk of HIV

[4] HIV/AIDS: The Basic Facts for Métis Communities. Published in 2003 by the Métis National Council. For more information, visit http://www.metisnation.ca/NEWS/PDFS/MNC-%20Aids%20Book-ENG%20j18.pdf)

infection to even the most remote Métis communities. In Northern and some rural areas, culturally appropriate counselling and HIV testing is almost non-existent, and outreach services are desperately needed.

The Métis have struggled throughout history to gain the same full recognition and rights under the constitution that other Aboriginal groups in Canada have long enjoyed. Although a Federal Interlocutor for Métis and Non-Status Indians does exist to work with Métis organizations to help place Métis issues on the federal agenda, the historic lack of recognition for a fiduciary responsibility towards the Métis put this culturally unique and separate Aboriginal group in a difficult position when it comes to addressing the health needs of their own communities. In September 2003, the Supreme Court of Canada recognized for the first time that there is a fiduciary responsibility to the Métis, but the terms of an agreement have yet to be clarified. More education and better information among the Métis in Canada is needed to guide HIV/AIDS prevention and control strategies, which translates into more funding for Métis specific programming and education. Partnerships between First Nations, Métis and Inuit organizations must be built to address the needs of the Métis in general Aboriginal HIV/AIDS programming. Governments and other agencies must respond to HIV/AIDS in Métis communities by ensuring that resources and services are culturally appropriate with access to counselling and HIV testing.

4.0 Key Successes of the Council 2001-2003

The first two years of the Council were both exciting and challenging for those sitting around the table. In addition to being charged with the considerable duties and responsibilities highlighted at the 1st and 2nd Aboriginal Summits on HIV/AIDS in Winnipeg and Calgary respectively, Council members needed to create an organizational structure and a host of internal procedures to govern itself. That first year saw the development of many such initiatives, among them the NACHA Terms of Reference, a communications plan, and an evaluation framework, many of which are still being worked on today as NACHA continues to define its itself and its role within Health Canada and in the community-at-large.

4.1 Establishment of mechanisms to ensure the effectiveness of Council

4.1.1 Development of Internal Procedures

Much of the first few months of the Council's existence was spent defining roles and developing internal procedures for the running of the Council. This development included the creation of a Terms of Reference for both the Council and the Co-Chair Committee, the election of Co-Chairs, the drafting of the Council vision, mandate, statements of diversity, representation and jurisdiction, Aboriginal persons living with HIV/AIDS inclusion statement, conflict resolution guidelines and the organization of caucuses.

4.1.2 Orientation Binder

With the Secretariat, an orientation package was prepared for Council members, that included all of the documents described in 4.11, as well as AIDS glossaries, epidemiological manuals, and other materials Council members would need to prepare themselves for the work ahead.

4.1.3 Role of NACHA

The Council, in a series of consultations, began work to define its role both within government and within the community. Presentations and consultations with various Health Canada divisions were arranged, so that dialogue could begin about NACHA's role, and how to best begin the process of absorbing various standing government committees into NACHA. The Council made concerns known to the department and scheduled meetings and presentations with branch and division heads to begin the consultation process and begin building relationships between Health Canada and NACHA.

4.1.4 Communications Plan

The co-chairs of NACHA undertook the development of a communications plan that ~~both~~ identified gaps in communication between NACHA, Health Canada and the Aboriginal community-at-large. Although still in draft stage, the communications plan includes plans for

such initiatives as the annual report, a NACHA website, a 'booklet' on NACHA activities and roles, and protocols for attending public meetings.

4.1.5 Evaluation Framework

NACHA began work on an evaluation framework to guide a formative evaluation which will measure and assess the performance and effectiveness of NACHA. The framework is meant to formalize a process and outline subsequent evaluation processes that can:

- enhance future operations;
- ensure informed decision-making based on solid data; and
- support an accountability function both to Aboriginal and non-Aboriginal stakeholders and government.

4.2 Supporting the Development of Critical Initiatives

One of NACHA'S key roles in the past two years has been to support the development of critical initiatives within Health Canada. Much of this work was done, and continues to be done, within community-based organizations, with NACHA lending its voice to these organizations and continuing to raise the concerns of these groups at the federal, provincial and regional government levels. NACHA has proposed and advocated for many of the following with Health Canada over the past two years.

4.2.1 Aboriginal Community-Based Research Relocation Process

NACHA met with government officials to raise the issue of the necessity and importance of community-based research in Aboriginal communities. One of the most immediate issues dealt with was the relocation of the Aboriginal Community-Based Research (CBR) Program, stressing the importance that the program be housed within the community and that the funding for this project to remain within the HIV/AIDS community. NACHA provided advice and input into the letter of agreement and transfer of the community-based research program from Health Canada to the Canadian Institutes of Health Research (CIHR).

In addition, NACHA struck a Community-based Research working group responsible for continuing the dialogue between NACHA, community and government concerning the on-going development of Aboriginal community-based research in Canada, including setting ethical standards for this research and helping to establish criteria for funding under various government CBR funding initiatives.

4.2.2 Epidemiology and Surveillance

The transition between the old Laboratory Centre for Disease Control Aboriginal working group on HIV/AIDS and NACHA was a smooth one, with many of the same issues being carried forward into discussions with the new Council. NACHA has continued to stress the importance of a strong and open dialogue between Aboriginal community members and the Surveillance and Risk Assessment Division (formally known as the HIV/AIDS Epi and Surveillance Division), as well as adherence to the principles of OCAP (Ownership, Control, Access and Possession) in

HIV/AIDS research and surveillance, and the necessity of standardising and improving ethnic and surrogate marker reporting in order to effectively target prevention efforts in Aboriginal communities.

Over the past two years, the Council has met often with surveillance officials at Health Canada to discuss these issues, as well as made presentations on the role of the Council to the bi-annual epidemiology and surveillance meeting of the Centre for Infectious Disease Prevention and Control (CIDPC) in Victoria in 2003.

When NACHA was first developed, a special standing committee was developed to look at the issues of epidemiology and surveillance. The committee included First Nations, Inuit, Métis and community representatives from NACHA along with technical and content experts from CIDPC and known as the NACHA Epi and Surveillance Subcommittee (NESS). In September of 2002, NACHA reviewed and subsequently revised its consultation process. In order to reduce member workload, increase capacity more broadly, standardize consultation across the branches of Health Canada, and expedite decision making, standing committees were replaced by ad hoc committees. The Epidemiology and Surveillance Ad Hoc Committee is currently collaborating on its first initiative, an Epi Note on Aboriginal Persons in Canada. The group meets regularly by teleconference and last met face-to-face meeting in January of 2004. Dissemination of the Epi Note is planned for the Aboriginal Summit in April 2004.

4.2.3 HIV/AIDS Aboriginal Programs

NACHA has been monitoring and advising Health Canada on the specific HIV/AIDS Aboriginal programs within Health Canada, such as the HIV/AIDS programs within the First Nations and Inuit Health Branch (FNIHB), and the Non-Reserve and Urban funding envelopes under the CSHA, NACHA is currently in the process of actively advocating for more funding for Aboriginal issues in the CSHA, as well as changes to how this money is distributed and accounted for. Some of the other issues/concerns that NACHA has addressed over the course of the past two years have been:

- staff-turn-overs at Health Canada and how this affects government relationships with community-based organizations;
- delays and lapses in funding and the effect this has on prevention and care in the community;
- how funding is distributed among Aboriginal organizations in Canada;
- concerns about Aboriginal specific funding being used to replace AIDS Community Action Program (ACAP) funding instead of augmenting it as was originally intended;
- the lack of operational funding for Aboriginal AIDS service organizations, and;

A NACHA Resource Allocation Committee has been developed specifically to look at some of these issue.

4.2.4 National Aboriginal AIDS Awareness

One of NACHA's key initiatives over the past two years has been to promote Aboriginal AIDS Awareness both within Health Canada and Correctional Service Canada (CSC) and within the Council itself. NACHA members bring specific cultural and community perspectives to the advisory process, as well as act as a conduit directly into the federal government to highlight emerging HIV/AIDS issues as they arise within the Aboriginal community. An Emerging Issues Working Group was established in order to identify emerging issues, prioritize them and recommend how NACHA should address those issues. The next step for this group is to provide advice to Health Canada on these issues.

In addition, a Council member sits on the National Steering Committee on HIV/AIDS Awareness to develop a campaign to put HIV/AIDS issues **"**back on the map" and to increase media coverage of HIV/AIDS issues within Canada. The NACHA representative ensures that Aboriginal issues are fully addressed on this committee.

4.2.5 Adequate Structure for the Canadian Strategy on HIV/AIDS

One of NACHA's key roles in the past two years has been to advocate for the increased cost effectiveness of the CSHA and to ensure effective collaboration between groups and departments under the Strategy when it comes to approaching Aboriginal HIV/AIDS issues in Canada. The Council approaches this on several fronts.

The first is to work with Health Canada to clarify and define mechanisms under the Strategy to improve the response to the epidemic in the Aboriginal community in Canada. In 2001, the first annual CSHA direction-setting meeting was held at Gray Rocks Inn in Quebec. It was attended by 125 experts who represented the range of CSHA partners, including representatives from NACHA and the Aboriginal community. Since that time NACHA has been working with Health Canada to ensure that two specific directions from this meeting are continually addressed. These are direction # 2: Build Unique Approaches for Aboriginal Peoples Within the CSHA, and direction #8: to Engage Vulnerable Canadians under the CSHA.

With these two directions in mind, NACHA has been in consultation with Health Canada, along with various community groups such as the Canadian Aboriginal AIDS Network, to ensure these directions are adhered to in all Health Canada policy and to make an improved Aboriginal Strategy with the CSHA a reality.

NACHA made several recommendations over the course of the two years in order to improve Aboriginal participation within the Strategy and to improve effectiveness of the Strategy in the Aboriginal community. NACHA has been working closely with Health Canada and CSHA partners to achieve goals set out at the direction setting meeting in Grey Rocks concerning Aboriginal populations. In particular~~ly~~, NACHA has been involved in the following initiatives under the Strategy:

- the 5 Year Review of the Federal Role in the CSHA. A NACHA member on sat the advisory committee for this review and NACHA had an opportunity to provide feedback on a teleconference call and by e-mail. NACHA will formulate a response to the final document.

- the Aboriginal HIV/AIDS Strategy. Health Canada has asked that NACHA comment on the Strategy.

4.2.6 Third Aboriginal Summit on HIV/AIDS

Part of NACHA's mandate is to ensure regular consultation with the Aboriginal community-at-large, both by seeking direct community input into Council issues and by holding a bi-annual Aboriginal HIV/AIDS Summit to elect new Council members. The next summit will take place in the late spring of 2004.

4.2.7 Liaison with Canadian Strategy on HIV/AIDS Partners

NACHA has established links with various CSHA partners and members of the Aboriginal and Non-Aboriginal HIV/AIDS community. Listed below are some of the organizations that NACHA has made connection and linkages with, and continues to work with to ensure the needs of Aboriginal communities in relation to HIV/AIDS are being met. These organizations are:

- Ministerial Council On HIV/AIDS
- Canadian Aboriginal AIDS Network
- Canadian HIV/AIDS Legal Network
- Canadian AIDS Treatment Information Exchange
- Canadian AIDS Society
- National Aboriginal Health Organization
- Canadian Inuit HIV/AIDS Network
- Métis National Council

5.0 Future Challenges

The Council has met many challenges over the past two years, and will continue to provide advice and direction to the federal government on Aboriginal HIV/AIDS issues in the future. Although the role of NACHA has yet to be fully defined under the new Canadian Strategy on HIV/AIDS, it is anticipated that NACHA will play a strong role, along with the community, in the development and implementation of an Aboriginal HIV/AIDS Strategy within the CSHA, as identified in direction #2, established at the direction-setting meeting at Gray Rocks.

In addition, NACHA has identified the following issues to be addressed at future meetings.

1) Social Capital

Social capital refers to the institutions, relationships, and norms that shape the quality and quantity of a society's social interactions. Increasing evidence shows that social cohesion is critical for societies to prosper economically and for development to be sustainable. Social capital is on the agenda for the Grey Rocks meeting scheduled for Montreal in 2004, and NACHA has made a commitment to look at issues of social capital in the Aboriginal community to bring the table during these discussions.

2) Community-Based Research

NACHA will continue to work with governments, academic institutions, and community to ensure the development of Community-based Research within the Aboriginal community as it relates to HIV/AIDS issues, and to continue to promote the principles of OCAP when it comes to gathering, developing, designing, and implementing CBR programs among Aboriginal people in Canada.

3) CSHA

NACHA's role in strengthening the Aboriginal portion of the Strategy is ongoing. NACHA representatives will continue to be involved in all consultations concerning the CSHA, to ensure that Aboriginal concerns are addressed and responses strengthened.

4) NACHA Roles And Representation

Another future challenge facing the Council is to continue to clarify the role of NACHA in relation to Health Canada and to the communities from which NACHA membership is drawn. In addition, as the membership of the Council changes over time, NACHA will need to continue to develop internal procedures that ensure consistency in the way it fulfills its advisory role within Health Canada.

6.0 Conclusions

In the two years since its inception, NACHA has accomplished much, both in terms of its role under the CSHA and within the community, and in terms of its own internal development. Its relationship to Health Canada will continue to change and evolve as the epidemic shifts and changes. As well, many of the initiatives and critical challenges described above will continue to be the focus of the Council. Some of these, such as CBR, are in their infancy, while others, such as the relationship of Aboriginal activists with the Surveillance and Risk Assessment Division, have a long and successful history.

Another of the important aspects of the Council, however, has been its success in bringing disparate and distinct populations together, to speak as one voice when needed, and to highlight differences of approach needed for each community. NACHA can serve as a model for other communities on how to set aside political differences for the sake of a single, important issue, and to educate each other in ways of doing things in a specific cultural context. The federal government also benefits from this inter-population collaboration, as members from various branches within Health Canada receive many perspectives at once, and can work with NACHA to achieve consensus on the best way of approaching issues of culture and diversity within the Aboriginal community across Canada when it comes to dealing with Aboriginal HIV/AIDS issues.

7.0 - Glossary of Terms

ACAP - AIDS Community Action Program
AIDS - Acquired immune deficiency syndrome
CBR - Community-based Research
CIDPC - Centre for Infectious Disease Prevention and Control
CIHR - Canadian Institutes of Health Research
CSC - Correctional Service Canada
CSHA - Canadian Strategy on HIV/AIDS
FNIHB - First Nations and Inuit Health Branch
HIV - Human Immunodeficiency virus
IDU - injection drug users
LCDC - Laboratory Centre for Disease Control
MSB - Medical Services Branch
MSM - men who have sex with men
NACHA - The National Aboriginal Council on HIV/AIDS
NESS - NACHA Epi and Surveillance Subcommittee
OCAP - Ownership, Control, Access and Possession
SMARTER - specific, measurable, attainable, realistic, time-limited, effective, relevant

Appendix 1.0 - Meetings of NACHA

Over the course of the last two years, there have been many meetings held in the evolution of NACHA. Some of these took place even before the Council was officially formed in Calgary. These key milestones as identified by NACHA are as follows:

- **March 2000, Winnipeg – First Aboriginal Summit On HIV/AIDS**

In July of 2000, Health Canada sponsored the first Aboriginal HIV/AIDS Information Sharing Meeting in Winnipeg (see Appendix 4) to discuss the creation of NACHA. Representatives from community-based Aboriginal AIDS organizations, political groups such as the Assembly of First Nations, The Métis National Council, Pauktuutit Inuit Women's Association and The Inuit Tapirisat were invited, and discussions on a national level were begun. Although resolution to what the Council should eventually look like and who should sit on NACHA was not achieved at this meeting, an Interim Working group to discuss the issues was created, and the process begun in an official capacity.

- **October 2000, Ottawa - Aboriginal Interim Working Group On HIV/AIDS**

As the precursor to the National Aboriginal Council On HIV/AIDS, this group spent an entire year discussing issues of representation and inclusion raised at the Winnipeg meeting. Finally a national summit was planned in Calgary and a process created to elect the first Council. This working group met for the first time in October of 2002 in Ottawa. In March 2001, the development of the first draft of the agenda for the Second Aboriginal Summit on HIV/AIDS.

- **May 2001, Calgary -- Second Aboriginal Summit on HIV/AIDS**

The Calgary Summit held in May of 2001 saw the election and creation of NACHA. (See Appendix 5). Six representatives from each of the four caucuses – Inuit, Métis, First Nations and Community – were chosen, and a mandate given by the summit to the new Council to address the shared concerns of the Aboriginal people about the escalating vulnerability of the Aboriginal population to HIV infection and to provide advice to Health Canada on HIV/AIDS issues that affect all of Canada's Aboriginal peoples.

- **September 2001, Vancouver - National Aboriginal Council on HIV/AIDS hosts its first face-to-face meeting.**

This first meeting saw the development of the draft Terms of Reference for the Council, the election of the caucus co-chairs, the drafting of the statements of jurisdiction, representation and diversity.

- **December 2001, Ottawa - National Aboriginal Council on HIV/AIDS hosts its first face-to-face meeting.**

Orientation on the Canadian Strategy on HIV/AIDS and Métis representatives attended their first meeting This meeting saw the attendance of the Metis caucus at the first meeting of the Council, and an orientation for the Council to the various departments at health Canada aligned under the CSHA.

- **May 2002, Edmonton – National Aboriginal Council on HIV/AIDS hosts its ~~third~~ second face-to-face meeting.**

Working Groups such as CBR and NESS and Resource Allocation were established and for the first time the full Métis Caucus participated in a meeting.

- **September 2002, Montreal – National Aboriginal Council on HIV/AIDS hosts its third face-to-face meeting.**

NACHA hosts its first full face to face meeting with all four caucuses fully participating.

- **January 2003,Ottawa - National Aboriginal Council on HIV/AIDS hosts its fourth face-to-face meeting**

NACHA hosts its fourth face-to-face meeting. with all four caucuses fully participating.

- **May 2003, Halifax, National Aboriginal Council on HIV/AIDS hosts its fifth face-to-face meeting.**

NACHA hosts its fifth face to face meeting with all four caucuses fully participating.

Appendix 2.0 - Directions From Grey Rocks

In 2001 the first annual CSHA direction-setting meeting was held at Gray Rocks Inn in Quebec. It was attended by 125 experts who represented the range of CSHA partners, including representatives from NACHA and the Aboriginal community. They came from national and regional non-governmental HIV/AIDS organizations; national Aboriginal organizations; national professional HIV/AIDS organizations; federal, provincial and territorial government departments; and the Ministerial Council on HIV/AIDS. These have become the 10 strategic directions that will guide the work of those involved in the CSHA over the coming years.

1. Mobilize Integrated Action on HIV/AIDS

Government departments at all levels, Aboriginal governments and community leaders will be mobilized to take coordinated and integrated action on HIV/AIDS, focussing on the determinants of health and on equal access to health care. This action will centre on people living with and vulnerable to HIV/AIDS.

2. Build Unique Approaches for Aboriginal Peoples Within the CSHA

A national Aboriginal HIV/AIDS Strategy will be built in collaboration with Aboriginal peoples and their chosen communities. The Strategy should be adequately funded, advance the unique needs of Aboriginal peoples, and be accepted by Aboriginal and non-Aboriginal stakeholders.

3. Build a Broad Information Strategy

A broad Strategy will be built to obtain and promote the use of HIV/AIDS information in the CSHA. Qualitative and quantitative research; national, regional and local data and statistics; and anecdotal information will be analysed and synthesized in an effort to stay abreast of the ever-changing nature of the epidemic.

4. Get Public Commitment, Political Leadership and Funding

A renewed commitment by political leaders, partners and the Canadian public is needed to expand Canada's response to the HIV/AIDS epidemic. Efforts will be made to mobilize politicians, bureaucrats and community leaders in all sectors and at all levels to obtain increased funding for federal, provincial, territorial and Aboriginal HIV/AIDS strategies.

5. Build a Strategic Approach to Prevention

A bold, innovative prevention Strategy that sets specific goals and outlines a step-by-step process to achieve them will be developed. This Strategy will be based on the principles that guide the CSHA and will include culturally specific programs.

6. Build a Strategic Approach to Care, Treatment and Support

A Strategy that ensures equal and seamless access to care, treatment and support for people living with HIV/AIDS will be developed. The Strategy will work to remove systemic barriers to access to care, treatment and support.

7. Renew and Develop Human Resources

In response to an overall need for revitalization of human resources with expertise in HIV/AIDS, the CSHA will renew and sustain broad-based intersectoral human resources in community, social service, health and other sectors.

8. Engage Vulnerable Canadians

Vulnerable Canadians must be engaged in an inclusive and empowering manner in order to build unique approaches that are flexible, innovative and measurable.

9. Move to a Social Justice Framework

The CSHA will move towards a social justice framework that will involve all sectors and levels of government, and --

what is perhaps most important -- will include vulnerable populations in policy and program development, implementation and evaluation.

10. Develop a Five-Year Operational/Strategic Plan

A long-term planning process for the CSHA is needed. As a result, a five-year operational/strategic plan will be developed, including the development of S.M.A.R.T.E.R. (specific, measurable, attainable, realistic, time-limited, effective, relevant) objectives for the CSHA.

Appendix 3.0 - NACHA Daft Terms of Reference

Mandate

To ensure the HIV/AIDS related needs of all Aboriginal (First Nations, Inuit and Métis) people of Canada are being met and to act as an efficient mechanism providing advice to Health Canada and other stakeholders about the needs of all Aboriginal people in Canada.

Purpose

The National Aboriginal Council on HIV/AIDS is a mechanism for the development and coordination of shared actions between the Canadian Strategy on HIV/AIDS and Aboriginal communities working on HIV/AIDS issues. This will ensure that the Government of Canada, its representative departments, and its provincial, territorial and municipal counterparts will be working with all Aboriginal peoples on all HIV/AIDS issues as they affect those in our communities.

Objectives

- To increase collaboration between all Aboriginal peoples and all other Strategy stakeholders
- To increase communication with all Aboriginal communities and all Aboriginal community members
- To increase the cost effectiveness of Canadian Strategy on HIV/AIDS resources
- To increase cross-cultural awareness and support in the work of the National Aboriginal Council on HIV/AIDS between all Aboriginal peoples and all non-Aboriginal peoples.
- To create one central committee to replace/absorb existing Aboriginal consultative committees of the Canadian Strategy on HIV/AIDS

Guiding Principles

As members of the National Aboriginal Council on HIV/AIDS, we are committed to the following principles of Unity, Common Values, and Vision.

Statements Of Unity

- We are committed to people living with and/or affected by HIV/AIDS and populations at risk for HIV infection.
- We agree to work together
- We are committed to support each other
- We are committed to a safe environment for open and honest dialogue
- We are committed to promoting the principles of OCAP; Ownership, Control, Access and Possession for all Aboriginal peoples.
- We are committed to a Council that encourages growth and supports regeneration, mentoring and capacity building.

- We are inclusive of all Aboriginal people in Canada regardless of how residence, geography, jurisdiction and status are defined.

Statements of Values

- We are committed to the values of equity, respect, diversity, autonomy, equality, meaningful support and balance among each population represented by the council and the individuals sitting on the council.
- We are committed to achieving Aboriginal representation for all Aboriginal peoples
- We recognize and promote holistic approaches to HIV/AIDS work in our communities.
- We recognize the variety of approaches to HIV/AIDS work in our communities and honour and respect the diversity of these approaches, including the models of harm reduction.

Statements Of Operational Values

- We are guided by our experience and not by our affiliations
- We will maintain flexibility and adaptability in implementing, monitoring and evaluating our yearly workplan.
- We shall be solution focussed.

Vision

- The National Aboriginal Council On HIV/AIDS will advise on all matters under the Canadian Strategy on HIV/AIDS as they relate to Aboriginal peoples.
- The National Aboriginal Council on HIV/AIDS will ensure effective collaboration and communications between governments, this Council, and all Aboriginal peoples in Canada.
- The Council will examine and advise around key issues to ensure equitable access to high standards of care and treatment, prevention and education for all Aboriginal peoples in Canada.

Qualities of Council Members

The following is a list of skills, qualities, abilities, knowledge and experience caucuses are encouraged to consider when choosing representatives for the Council.

- Strong capacity to effectively deal with a wide variety of political and non-political organizations
- Able to actively participate and effectively communicate ideas
- Strong expertise in HIV/AIDS policy / program development
- Ability to travel
- Knowledge and respect of Aboriginal diversity, governance and history
- Knowledge and respect for sexual and spiritual diversity

- Commitment to collaboration and cooperation

Responsibilities Of Council Members

- To provide informed advice to the National Aboriginal Council on HIV/AIDS based on broad consultation with the populations they represent

- To recognize that, within the confines of the Council, individuals may represent a specific Caucus, but when communicating externally about Council decisions, they represent the entire Council

Accountability of the Council

- The Council is collectively accountable to all Aboriginal peoples of Canada through the National Aboriginal Summit on HIV/AIDS and the Canadian Strategy on HIV/AIDS

- The Council is collectively responsible to Health Canada and other stakeholders as determined by the Council.

- Council members are individually accountable to the caucus whose interest they represent on the Council.

- Council members are individually accountable for broad-based communication and consultation with relevant organizations, peoples and/or systems.

Membership

The Council

The Council is an advisory, apolitical and multi-disciplinary group that consists of 24 Members with equal representation (six each) from First Nations, Inuit and Métis. An additional 6 members will represent Aboriginal AIDS Organizations and community-based Aboriginal organizations involved in HIV/AIDS and shall be chosen from the community caucus at the bi-annual Aboriginal summit on HIV/AIDS.

The Summit

Council members are chosen at the National Aboriginal Summits on HIV/AIDS held every two years. Summit are held to share information and knowledge about the Aboriginal HIV/AIDS movement in Canada. Individuals who are invited to attend the Summit will be asked to participate in one of the four caucuses at the summit: Community organizations, First Nations, Inuit and Métis, who will then meet and select their representatives to the National Aboriginal Council on HIV/AIDS. The membership selection process for the council is autonomous to each caucus. Participants will be invited by the co-chairs in partnership with Health Canada.

Summit Caucuses

Caucuses are strongly encouraged to support the inclusion of Aboriginal people living with HIV/AIDS within their council membership selections. Caucuses are also encouraged to consider members whose combined skills, knowledge, abilities and experience will enhance representation.

Terms of Appointment

- Council terms of office are for two years and reviewed at each Summit. Participants have the option of extending their term at the Summit. For each subsequent term commencing May, 2003, terms of appointment will be one year with an option of renewal.

Decision Making

Wherever possible decisions will be made by consensus (see NACHA glossary), cooperation and compromise. When consensus cannot be reached, a vote will be called. Voting will be based upon a quorum of 50% + 1 or 13 people. A vote will be carried by a 75% majority of those council members present. (This calculation will be rounded up to the nearest number.) Minority concerns will be noted and respected for the record.

Evaluation

- That we include all Aboriginal people in our evaluations of the effectiveness of the council. We will strive to provide opportunities so interested Aboriginal people can participate in an evaluation process that relates to the effectiveness of the Council.

- The work of the National Aboriginal Council on HIV/AIDS will be evaluated by participants at the bi-annual Aboriginal Summit on HIV/AIDS based on the workplan of the Council.

- An ongoing evaluation of these Terms of Reference will be undertaken on an ongoing basis.

Attendance

- Council members are asked to attend as many meetings of the National Aboriginal Council on HIV/AIDS as possible in the term of their appointment.

Membership Review

- Council members who miss two (2) meetings consecutively without a valid reason shall have their membership reviewed by a special meeting of their caucus at the end of the second meeting missed.

Proxy And Observers

- There shall be no positions of proxy designated for members of the Council at any time. Teleconference participation with individual caucuses for the purposes of decision making, constitutes active participation.

- No observers shall be designated to replace Council members at any time during council meetings.

- There will be no observers present at the meetings of the Council unless invited by the Council.

- Caregivers are not considered observers, but shall have a non-participatory role at Council meetings.

Secretariat

- Secretariat and other administrative duties for the National Aboriginal Council on HIV/AIDS shall be provided by Health Canada.

Appointment of Co-Chairs

- The appointment of Co-Chairs for the Council shall be made at the complete discretion of the individual caucuses.

Spokespersonship

- Public forum and meeting spokespersonship shall be determined by the Council, with proper briefing and preparation provided with assistance from the Council executive committee and the secretariat.

Meetings

- Face-to-face meetings of the Council are to be held quarterly, and as needed at the call of Council. Council teleconferences are held on an as-needed basis.

Appendix 4.0 - NACHA Membership List, as of March 2004

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